

Tenderhearts



I am a Caregiver. What's Next?

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Buzz Words

- **formal caregiver:** a caregiver who works for a service industry as a paid employee or volunteer (e.g., nursing assistant)
- **family or informal caregiver:** a caregiver who generally receives no pay – usually a family member, friend or neighbor
- **working caregiver:** any caregiver who maintains a paying job in addition to the caregiving role
- **primary caregiver:** a caregiver who manages the care recipient's personal affairs and daily routine of care
- **sandwich generation:** those who are forced to balance financial, physical and emotional needs of their children with those of an aging parent

Scenario

The phone rings, awakening you from a deep sleep. It is your 84-year-old father calling to tell you that your 80-year-old mother has fallen. The prognosis: a broken hip. He starts crying. He doesn't know how he can take care of her. His arthritis makes it impossible to answer the phone at times, much less lift another person.

Your sister lives two states away. You offer words of comfort to your father and a promise that you will take care of them both. You hang up the phone and realize you have just entered the world of caregiving. Welcome!

Facts

If someone were to ask you to define a caregiver, could you? Caregivers play many roles in our society: They are all ages, represent all races, and can be male or female. The Family Caregiver Alliance (2003) defines a caregiver as anyone providing assistance to someone who is incapacitated to some degree and needs help.

Definitions also differentiate between *formal caregivers* and *informal* or *family caregivers*. *Formal caregivers* work for a service industry as an employee or a volunteer (e.g., nursing assistants). *Family caregivers* generally receive no pay and are usually family members, friends or neighbors. In 1997, the National Alliance for Caregiving and American Association of Retired Persons reported that care for a person age 50 or over occurred in approximately one out of every four households. Family caregivers can provide care either part time or full time.

As Baby Boomers (those born between 1946 and 1964) age, many of them are becoming a part of the *sandwich generation*. According to the American Health Care Association (Sept. 1998), the *sandwich generation* refers to those who are forced to balance paying for their children's education while caring for an aging parent. Many of the sandwich generation maintain careers outside the home. The strain of caring for the parent, raising their own children, and various periods of time away from the job to care for parents or children places the them in a financially stressful situation. Plans for their own retirement are threatened as they work fewer hours for pay and spend more time caring for their aging parent(s). The sandwich generation

caregiver – or any caregiver who maintains employment outside of the caregiving role – is referred to as a *working caregiver*.

No matter how caregiving is categorized, the role is frequently fraught with long hours, endless work, and periods of feeling overwhelmed and out of control. You are not alone!

Caregiving Roles

Most people did not grow up thinking they would some day be a caregiver assisting a loved one. Many in our society view family caregiving as that “other thing” you do at home. “You know, what you do after leaving the office.” Caregiving can be overwhelming – even on a good day with your loved one. On a day when the care recipient is ill, “overwhelming” is an understatement, even more so if the caregiver is also employed and taking care of children and a spouse.

As the health of the loved one deteriorates, the family caregiver often assumes the role of being the *primary caregiver*. The primary caregiver manages the personal affairs and daily routine of care for the loved one. Assuming the role of a primary family caregiver does not mean that you merely begin taking care of another person. It means assuming the role of managing another house, or if it is your spouse, you may manage what he/she no longer can. Whether the loved one lives with you or remains elsewhere, you may be overseeing their health needs and financial affairs. Bills have to be paid, houses cleaned, doctor appointments arranged, finances managed, etc. You may ask, “Where do I begin?”

Preparing for Your Role

Rarely are caregivers given the luxury of time to prepare for the role. Many find out with a phone call that a loved one is ill or needs help. If you fit this category and did not have time to prepare for your role, do not worry. Find out what needs to be done to smooth the caregiving journey for you and your loved one. Then take the next step toward becoming an informed and empowered caregiver.

The checklist below will help determine your caregiving responsibilities and what areas may need to be addressed.

Determine what type of caregiver you are:

Spouse, adult child, grandchild, relative, friend, neighbor; full-time, part-time; long distance, nearby, in-home; primary caregiver, frequent assistant, occasional assistant

Which areas are you responsible for in the care of your loved one?

Legal decisions, financial decisions, medical decisions, emotional well-being, personal hygiene, dietary needs, transportation, home maintenance

Do you have legal power to make decisions?

Do you have durable power of attorney for healthcare decisions or durable power of attorney for financial decisions for the care recipient?

Do you know your caregiving team?

Physicians, geriatricians, geriatric care managers, nurses, physical therapists, dietitians, social workers

Do you know what type of disease or illnesses your loved one has?

Are you familiar with the symptoms and progression of the disease or illness?

What are the current medications?

Dosage? What is the purpose of the medication? When and how should the medication be taken?

How do you take care of your loved one's special needs? (e.g. disease management)

How do you decide when you can no longer give your loved one the care needed?

What options exist, if you need to make a change?

Respite care, assisted living, skilled nursing, universal housing

Have you and your loved one discussed the end-of-life issues?

Burial, cemetery, living will

First Steps

Now that you have determined the areas that still need to be addressed, rank them by order of importance. For example, if you marked *legal decisions*, *medical decisions* and *transportation* as areas of responsibility – and you have durable power of attorney for medical care, but not for financial decisions – obtaining durable power of attorney would be ranked as the most immediate issue. Although you have to pay the monthly bills for your loved one, you cannot take money from the bank account until you have the legal authority to do so.

If your loved one wants you to be responsible for finances, contact an attorney (preferably one certified to practice elder law). Request an appointment for both you and your loved one to obtain the durable power of attorney for financial decisions. If your loved one is not mentally competent to make these decisions, then a durable power of attorney will have to be obtained through a court order. The financial and legal decisions pertaining to your loved one can not be handled by anyone who does not have a durable power of attorney.

The next step in caregiving is to determine the current legal and financial status of your loved one's affairs. In the next column is a checklist to help decide which documents apply to your loved one. Obtain copies of the documents, and encourage your loved one to keep the originals in a safe deposit box that you share and a copy in another location (e.g., your *Tenderhearts Caregiving Journal*).

Personal Identity Documents	Original Located
Birth certificate	<input type="checkbox"/>
Driver's license	<input type="checkbox"/>
Divorce record	<input type="checkbox"/>
Marriage license	<input type="checkbox"/>
Military discharge certificate	<input type="checkbox"/>
Social Security card	<input type="checkbox"/>
Spouse's death certificate	<input type="checkbox"/>
Insurance Policies	
Accident	<input type="checkbox"/>
Auto	<input type="checkbox"/>
Dental	<input type="checkbox"/>
Disability	<input type="checkbox"/>
Health	<input type="checkbox"/>
Homeowner's	<input type="checkbox"/>
Liability	<input type="checkbox"/>
Life	<input type="checkbox"/>
Long-term care	<input type="checkbox"/>
Medicare benefits information	<input type="checkbox"/>
Medigap/supplemental	<input type="checkbox"/>
Prescription	<input type="checkbox"/>
Social Security benefit information	<input type="checkbox"/>
Veteran's benefit information	<input type="checkbox"/>
Vision	<input type="checkbox"/>
Financial Documents	
Annuity contracts	<input type="checkbox"/>
Checkbook	<input type="checkbox"/>
Contracts	<input type="checkbox"/>
Credit cards	<input type="checkbox"/>
Home equity loan	<input type="checkbox"/>
Income tax returns	<input type="checkbox"/>
IRA/401(k)	<input type="checkbox"/>
Mortgage papers	<input type="checkbox"/>
Pension plan	<input type="checkbox"/>
Personal loans	<input type="checkbox"/>
Property deed	<input type="checkbox"/>
Savings accounts	<input type="checkbox"/>
Stock and bond certificates	<input type="checkbox"/>
Vehicle loan/lease	<input type="checkbox"/>
Vehicle title	<input type="checkbox"/>

End-of-Life Documents

Advance medical directives

(e.g. Do Not Resuscitate)

Burial agreement

Durable power of attorney

for health care

Durable power of attorney

for financial decisions

Guardianship

Living trust

Last will and testament

(e.g. estate will)

Organ donorship

Prepaid funeral plan

Original Located

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